# FULL COUNCIL MEETING MINUTES May15, 2017 - 1:30 PM STATE COUNCIL FOR PERSONS WTH DISABILITIES Edgehill Training Room/DPH, Dover

## **PRESENT**

Jamie Wolfe, Chair; Gene Aucott, Easter Seals; Susan Burns, DSCYF/DPBHS; Sonya Dyer, Dover AFB; Moni Edger, United Cerebral Palsy of Delaware; Nick Fina, Advocate; Brian Hartman, DLP/CLASI; Terri Hancharick, EPIC; Linda Heller, Linda Heller, HLADE; Jocelyn Langrehr, DOL/DVR; Karen McGloughlin, DPH; Jim Miller, Polio/Post-Polio Support Group (via phone); William Payne, Advocate; Loretta Sarro, DOL/DVR DODHH; Lloyd Schmitz, Council of the Blind; Sybil Brown, GACEC (for Wendy Strauss); John McNeal, Staff; Amber Rivard, Support Staff; Dee Rivard, Support Staff and Jo Singles, Support Staff.

### **GUESTS**

Victoria Counihan, DOJ/AG
Elizabeth Suarez-Gonzalez, Attendant
Jim Steele, National Federation for the Blind in Delaware

Interpreters: Ruth Fisher and Deb Monhollan

#### **CALL TO ORDER**

Jamie called the meeting to order at 1:32 pm. Everyone introduced themselves.

#### ADDITION OR DELETIONS TO THE AGENDA

Addition: Revised SCPD Website

# **APPROVAL OF MINUTES**

Lloyd made a motion to approve the minutes and Brian seconded the motion. The minutes were approved as submitted.

#### **BUSINESS**

### H.B. 160 - Assisted Suicide/End of Life Options Legislation

Jamie spoke about this type of bill in other states and how it negatively affects the disability community. Jamie stated that she has mixed feelings about the legislation. Brian will do a deliberate analysis of this legislation for Policy & Law Committee for discussion at the June 8<sup>th</sup> meeting, 9:30 am, Smyrna Rest Stop Conference Room. The Policy & Law Committee meeting is open to the public and interested folks are welcome to attend. The meeting is also listed on the State Public Calendar. Brian added that the LIFE Conference Design Team will have a session on the pros and cons of this legislation during the LIFE Conference in January, 2018. John plans to reach out to Representative Baumbach. John thinks he should hear from both sides of the debate. John has a couple of names on the opposing side. Brian commented that the proposed legislation is not moving on the fast track. John reviewed the legislation and noted that the medicine is self-administering so someone with a disability cannot

administer the medicine themselves, this would not be an option for them. Also, there is a concern that, if the legislation is more broad reaching to people with disabilities, it could lead to a "slippery slope" in a greater way than how it is currently written. John added that Oregon currently has an ADA lawsuit filed against them because it violates the ADA. He will check on the status of the lawsuit. Brian commented that H.B. 160 was introduced on May 2 and is still in Committee. John stated that if it does come up in Committee and people are interested in the dialogue, he will send out an alert to indicate that it is in Committee. Brian commented that Representative Baumbach is amenable to changes and has reached out to the disability community for comments and input.

### **Custie Award Process**

After everyone read and reviewed the latest version of Nick's document, incorporating comments from the March 20<sup>th</sup> SCPD meeting. John referenced another handout—Custie Award Recommendations. After discussion, Dee suggested that the Delaware Women of the Year Award uses 250-500 word limits for most of the blocks, with a 750 maximum word limit for the narrative. Recommendation was made that the Nomination Form blocks have a word limit as follows:

Informational summary: 250-500 word maximum Specific achievement(s): 250-500 word maximum

Timeframe: 250-500 word maximum

Benefits for community of persons with disabilities: 250-500 word maximum

Role of Nominee: 250-500 word maximum

Narrative: 750 word maximum

Brian commented that the voting process was unduly cumbersome and recommended keeping the process simple using a simple majority vote, similar to how other important decisions are made. Nick commented that he was not opposed to this. Victoria commented that if we wanted to change the process from a simple majority that would have to be voted on. Brian spoke about his concern about a group sharing a Custie award. Clarification was made that each person would get an award for a specific contribution.

Brian commented that there were no limits set on the number of attachments or appendices. This could present a problem. Attachments and Appendices were discussed, and recommendation was made that this would be allowed because it could be important in making a decision. There was discussion about the timeframe. It was noted that nominations needs to be voted on by August 31<sup>st</sup> so the awards can be ordered in time for the October 16<sup>th</sup> Annual SCPD Luncheon.

Nomination will be received until August 1<sup>st</sup>. The Awards Committee could then submit their findings by September 1<sup>st</sup>. It was clarified that this Committee would not submit a recommendation, but screen out unqualified nominations. Karen commented that screening out is subjective. Jim Miller recommended having a Committee of five representing five disabilities. He also suggested that the Committee work out the time frame. Jamie spoke about no one with an intellectual disability has ever won an award. She added that part of it is that no one with an intellectual disability is represented on the Council and there needs to be across disability emphasis. This will be developed over the next year. Jamie also suggested that the form should not be so professional so that people with intellectual disabilities or reading issues can be accommodated. Brian noted that we may be skewing the process so that professionals are nominated rather than non-professionals. Victoria suggested that the sentences could be restructured on the form that is more understandable. Recommendation was made to make the wording less professional. Linda commented that we want to ensure that the process is as fair as possible. John recommended having a fillable form online. Karen suggested reaching out to other groups to increase participation. Susan spoke about the Committee screening in and screening out

nominations. Brian commented that the award(s) could be given at the LIFE Conference if the time seems too compressed. He also commented that nominations could be taken by the Committee and also the floor.

John stated that there has not been an overwhelming number of nominations in the past. He would like to see a more robust impact in nominating people. The marketing needs to be expanded. He suggested scaling back the Awards Committee for this year. SCPD staff could ensure that nominations are complete. This may be changed depending on the outcome from this year. Brian suggested reaching out using social media, advertisements in the News Journal and Dover Post. Dee suggested having an advisory group that would not have to meet in person and staff could ensure that all nominations are emailed in PDF form. She added that they then could be ranked.

Jamie spoke about two possible options: Vote on the floor now or table it until the June meeting. Nick commented that he thought that any more discussion was unnecessary. He will try to capture points discussed today. He will send these to John and Jamie for dissemination to the Full Council. Brian commented that we owe Nick much appreciation for all the work he has done on improving the Custie Award process. Nick commented that he feels the Custie Award reflects what this Council is about.

# <u>Update – Meeting with Congressional Legislators re: Medicaid</u>

Jamie spoke about the deadline for the Home & Community Based Rule under Medicaid has been moved back three years. The Rule says that if you have a Medicaid Waiver for Home & Community-Based Services, there are certain ways that the money behind the Medicaid Waiver is to be used. If it looks like an institutional setting as opposed to a home and community-based setting, there could be heightened scrutiny on the place of residence. Medicaid and CMS (Center for Medicaid & Medicare Services) have been working on changes, but have delayed implementation for three years. A major concern is that within the three years, a lot of places could be built, for example, institutions or intentional communities. A lot of Medicaid funds could be spent on institutionalization in the next three years which could have a major impact on Home & Community-Based Services. Jamie suggested contacting Delaware's Federal Legislators—Senators Coons and Carper and Representative Rochester by letter or meeting with them. Terri added that Washington, DC wants to keep the ball rolling toward Community-Based Services and the Transition Plan. She noted that some agencies are saying that they need more time and will not have it done by 2019. She also stated that the intent is not to roll back, but give the agencies more time to change their business plan and the way they are doing business. Brian clarified that this does not change the dates for the planning; it only addresses implementation. The planning will continue to move forward, although implementation will take longer. Linda asked about other states that have intentional communities and asked if the letter pertained only to Delaware. Brian stated that Governor Markell was writing a letter as the Governor of Delaware saying that CMS should change their approach, but they have not.

Jamie stated that if people have concerns about changes in policy in regard to the CMS Ruling to send an email to John, Jamie and Jo. The concerns can be discussed as an agenda item for a future Council meeting. John suggested if someone has someone at a local, State or federal level that they wish to invite to a meeting, to let him know.

Brian noted that the DMMA, submitted a Transition Plan Amendment on April 21, 2017. It can be found on the following link: <a href="http://www.dhss.delaware.gov/dhss/dmma/files/de hcbs transition amendment.pdf">http://www.dhss.delaware.gov/dhss/dmma/files/de hcbs transition amendment.pdf</a>. The document contains some charts with the number of assisted living and day habilitations that would determine complaint, compliant with modifications, or qualifying for heightened scrutiny (including DDDS and non-DDDS). Only one entity qualified for heightened scrutiny. Brian added that his staff is working on communication with CMS questioning this and it will be sent later this week. They have

also met with DMMA to discuss assisted living. He stated that there are a number of assisted living facilities located on the campus of some nursing homes. They are unsure about assisted living facilities receiving home & community-based services on the campus of a nursing home. Terri asked that we keep the conversation going on this.

## **Update Accessible Parking Legislation**

Brian stated that the Council voted to support a communication with requesting a meeting with New Castle County representatives to address an ordinance and approach to accessible parking which currently violates the ADA. Laura Waterland of his staff sent a letter to the County Executive on April 18th requesting a meeting to discuss these anomalies with DLP staff and John. Currently, the letter is being reviewed by NCC, but a formal response has not yet been received. Jamie and John thanked Brian for his update. Karen asked if they were looking at other County governments. Brian stated that NCC violates the ADA, but Kent and Sussex County has not yet been reviewed. John commented that NCC is the greater challenge and if we get them onboard, Kent and Sussex Counties governments may follow their lead. Karen commented that it would be good to tackle all the County governments one at a time. Linda asked if John would be working with the Architectural Accessibility Board (AAB) since they have brought up this issue several times over the years. John stated that he can reachout to the AAB and report back.

## **Revised SCPD Website**

John displayed and reviewed revisions to the SCPD website, including new drop-down tabs. There will be continued work on updating the website with new Success Stories, etc. Additional resource links will be added. He noted that the Brain Injury Trust Application form is now fillable online, but can also be printed and mailed if needed. There is also a contact phone number for people to call if they have questions. Positive comments were received. John asked everyone to provide suggestions or additional information to improve the webpage. The link for the SCPD webpage is: <a href="http://scpd.delaware.gov/">http://scpd.delaware.gov/</a>.

John spoke about his role as administrator. He wants to provide what the Council wants and needs. He urged everyone to contact him with potential speakers on important issues. He would also like to discuss future agenda items at the end of each meeting. Jamie commented that many emails Kyle previously received need to be sent to John and gave an example. John asked everyone to check their distribution lists. Susan suggested adding the Paratransit Application to the webpage and Dee will make sure it is added. Nick suggested having the forms built into the appropriate Sections. Dee clarified that it is located twice (under the Forms tab and the appropriate Section).

#### Other Business

Loretta asked if John has a meeting scheduled with Peg Stewart re: Interpreting regulation. John stated that a meeting has been scheduled in the next week or so.

## **ANNOUCEMENTS**

Jamie commented that she will not be able to attend the June meeting due to meeting conflicts with Junior Partners.

Karen spoke about an upcoming 2017 Health Equity Summit at Delaware State University on June 29, 2017 (8:30 am – 3:00 pm). Health Neighborhoods and Opiate Abuse will be topics on the agenda. She will forward the flyer to John for distribution, including a Registration link.

Sonya spoke about the Open House at Dover AFB during the last weekend in August. They are planning a preview day (Friday) for children with special needs and disabilities. More information will be coming out and she will share it with the Council via John.

# **PUBLIC COMMENT**

None

### **ADJOURNMENT**

Brian made a motion to adjourn. This was seconded by Lloyd and approved. The meeting adjourned at 3:17 pm.

Respectfully submitted,

Jo Singles Administrative Specialist

SCPD/min/may17